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# A Bridge to One World: An Indigenous Wisdom-Based Approach to Designing a Transcultural Patient Family Advisory Council

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Running head: STORYTELLING, RITUAL, AND DIALOGUE

A Bridge to One World: An Indigenous Wisdom-based Approach to Designing a  
Transcultural Patient Family Advisory Council

Julie Lundberg

Submitted in partial fulfillment of the  
Requirement for the degree of  
Master of Arts in Nursing

AUGSBURG COLLEGE  
MINNEAPOLIS, MINNESOTA

2011



**Augsburg College**  
**Department of Nursing**  
**Master of Arts in Nursing Program**  
**Thesis or Graduate Project Approval Form**

This is to certify that **Julie Lundberg** has successfully defended her Graduate Project entitled "**A Bridge to One World: An Indigenous Wisdom-based Approach to designing a Transcultural Patient Family Advisory Council**" and fulfilled the requirements for the Master of Arts in Nursing degree.

Date of Oral defense **December 5, 2011.**

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**Abstract**

As health care organizations face increasing challenges to accommodate diverse patient populations amid growing concerns of persistent health disparities, there is urgent need to better understand and listen to diverse, unique patient experiences. This paper describes the design and implementation of a transcultural Patient Family Advisory Council (PFAC) as a concrete step towards ensuring that the voices of culturally diverse patients and families are effectively engaged to improve the patient experience at a large, Midwestern healthcare organization. Storytelling, ritual and dialogue provide a wisdom-based approach to the design of a Bridge to One World practice model grounded in Leininger's Culture Care Theory of Diversity and Universality.

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## Chapter One

*Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.*

- Margaret Mead

The United States leads the world in healthcare spending, yet this expenditure has not translated into better health or assurance of access to high quality health care for all U.S. citizens (Mead, Cartwright-Smith, Jones, Ramos, Woods, & Siegel, 2008). Many Americans are struggling to get the quality health care they need, while over 49,000 Americans have no health insurance at all (U.S. Census Bureau, 2011, p. 26). This reality impacts racial and ethnic minorities in particular. Studies document that minorities are in poorer health, experience more significant problems accessing care and often receive lower quality health care than the majority of Americans (Agency for Health Care Quality and Research, 2008; Institute of Medicine, 2003). Furthermore, lower quality health care leads to poorer health and poorer health outcomes among minority populations. The fact that the U.S. population diversity is growing rapidly, mandates increased cultural responsiveness to the health care needs of all people and sharpened attention to reducing health disparities among and between diverse population groups. As a matter of national importance, health care organizations must implement interventions aimed specifically on increasing access to high quality culturally responsive health care and thus decreasing the inequities in health that burden minority populations.

Minorities comprise roughly one-third of the U.S. population currently, The U.S. Census Bureau (2008) projects that minorities will become the majority in 2042 and grow to 54% of the national population by 2050. By 2023, minorities will comprise more

than half of all children. The increasing diversity of the U.S. population has implications for all aspects of health care delivery. The Commonwealth Fund (2011) and other agencies have provided well established documentation of differences in health outcomes and quality of health care between minorities and non-Hispanic whites.

The need for transformation in healthcare system design and delivery models is critical. More specifically, it will be critical to shift from a *provider-centric care model* to one focused on actual persons who are seeking care, i.e. a *relationship-based model*. People today who seek healthcare expect greater participation in shaping their healthcare environment. Nevertheless, in these economically challenging and chaotic times, health care organizations are operating within a business model rather than a relationship-based model of care. For example, they are using social media and social marketing to advertise and *sell* their *products*. While the search goes on for better, more affordable care, in the face of growing pressures for cost containment there is tremendous tension between the business of healthcare and the caring practices of healthcare. Within this gap there is great opportunity for transformation. The tension is fueling the evolving national healthcare quality movement emphasizing transparency, patient-centeredness, and organizational accountability. The paradigm is slowly beginning to shift from a business model to a caring model. Quality organizations want hospitals to collect more data that focus on patients and patient outcomes rather than processes and payment plans (Scott, 2010).

This paradigm shift is supported by federal efforts. The Affordable Care Act establishes a National Quality Strategy that sets priorities to guide the effort to increase access to high-quality, affordable healthcare for all Americans (U.S. Department of

Health and Human Services, 2011). In March 2011, the Congress released a report on the National Strategy for Quality Improvement in Healthcare. One of the six top priorities for improving quality is listed as “ensuring person-and family-centered care” (Report to Congress, 2011, p. 10). The following excerpt from the Report to Congress (2011) aptly describes a shift to a relationship-based, or *client-centric system* that emphasizes a client-provider partnership and culturally congruent care. Furthermore, it supports the call to advance patient-family-centered care (PFCC):

Healthcare delivery in the United States is often not designed around meeting the needs of the patient. Instead, clinical services are often organized around specific clinical conditions and designed with little input or direction from the patient. We need to change that. Health care should give each individual patient and family an active role in their care. Care should adapt readily to individual and family circumstances, as well as differing cultures, languages, disabilities, health literacy levels, and social backgrounds. (Section II, p. 10)

Numerous national organizations have supported patient-family centered care approaches to health care improvement. The Institute of Medicine (IOM) established that patient-centered care is care that is respectful and responsive to patients' preferences, needs, and values (2001). The Joint Commission recently released recommendations to help hospitals address unique patient needs and new patient-centered communication standards. The Roadmap for Hospitals (2010) provides clear information and exemplary practices to inspire hospitals to advance cultural competence, effective communication, and patient-and family-centered care as ways to ensure quality and safety. As a result of a partnership with the U.S. Department of



Health and Human Services Office for Civil Rights, the Joint Commission (2010) supports language access and advancing health literacy in health care organizations deemed a critical aspect of safe, quality patient care, particularly for culturally diverse populations. The Joint Commission (2010) called for health care professionals to obtain direct feedback from patients and their families in planning for quality improvement and healthcare redesign.

Furthermore, the Institute for Healthcare Improvement with support of the Rx Foundation and The Robert Wood Johnson Foundation, developed best practices for hospitals supporting patient-centered care. Three areas of focus include involving patient and families in the design of care, reliably meeting patient's needs and preferences, and informed shared decision making (Jacob, 2010). In addition, the National Quality Forum (2007) endorses organization safe practices which articulate the role of direct patient input beyond satisfaction surveys. Rather, a structure or system should be established to obtain direct feedback from patients and families regarding the performance of the organization with existing services and programs and meeting unique needs. In other words, engaging the voices of patients and families is essential in the planning and delivery of care in health care organizations.

As health care organizations face increasing challenges to accommodate diverse patient populations amid growing concerns of persistent health disparities, there is urgent need to better understand and listen to diverse, unique patient experiences. DiGioia, Lorenz, Greenhouse, Bertoty, and Rocks (2010) emphasize the importance of accurately understanding the current care experience from the eyes of patients and families for meaningful and lasting transformational improvements. Brown (2009)

contends that empathy is the key to transforming observation to insight and inspiring action and urgency. Traditional surveys and focus groups methods fall short in service improvement and often lead to incremental improvements versus innovation and transformation. A sustained relationship is a better choice for true partnership and transformative change.

Across the United States, patient family advisory councils (PFACs) are part of the movement to make patient centered care come alive in healthcare organizations in a sustainable manner. PFACs belong to an integrated set of strategies used by healthcare organizations interested in instilling a family-centered care philosophy to improve health care and services provided (Halm, Sabo & Rudiger, 2006). There is a growing body of research to support family centered and culturally congruent care that improves care quality, safety and satisfaction, as well as clinical outcomes (The Institute of Patient-and Family-Centered Care, 2011). In addition, the patient-centered work done through PFACs has been linked to such outcomes as improved patient satisfaction, improved patient compliancy to treatment regimens and increased staff satisfaction (Meyers, 2008).

Benefits of patient-and family-centered care (PFCC) can be actualized across the continuum of care. In 2010, the Institute of Patient and Family Centered Care published a compendium of bibliographies providing evidence to support the advancement of this model of care. Over 1000 articles were listed which provides a substantial body of evidence to support that the experience of care is important and the active participation of patients and family members as advisors in clinical care, education, and program development will enhance outcomes. PFCC is a low technology approach that enables

caregivers to deliver exceptional care experiences by refocusing existing resources without additional staffing (DeGioia et al., 2010). Specifically, PFCC approaches have helped hospitals to financially benefit through reducing length of stay, number of admissions, operating costs, medical errors, number of complaints, and number of malpractice claims while also reporting increases in market share and employee retention rates (Charmel & Frampton, 2008; Hodges, 2009).

PFACs offer a sustainable, systematic way to include the patient-family voice in care planning and delivery. Viewing care through the eyes of patients and families enables caregivers to redesign care to improve outcomes without significant cost increases. Caregivers can be defined as any person in the health care setting whose work touches a patient's or family's care experience including nurses, physicians, therapists, technicians, dietitians, appointment schedulers, parking attendants, and housekeeping, as well as hospital leaders, purchase and supply chain employees and financial representatives whom patients and families may never see (DeGioia et al., 2010). This definition empowers all people in the healthcare system to make contributions to address issues and solve problems. It expands accountability and encourages a model of collaboration to build the ideal patient experience.

### **Purpose of the Project**

The purpose of this project is to use an Indigenous wisdom-based approach to design the implementation of a transcultural patient family advisory council at a large, Midwestern health care organization. This Indigenous wisdom-based approach will incorporate three Indigenous ways of being and relating to others---storytelling, ritual and dialogue---into the design and implementation process. Storytelling, ritual and

dialogue are powerful ways of illuminating the meaning and expressions of care and caring transculturally. Guidance and support for this project are grounded in Madeline Leininger's (2006) Theory of Culture Care Diversity and Universality.

### **Significance of Project**

Despite the number of PFACs increasing nationally, few, if any, are grounded in transcultural nursing theory and practice. Additionally, there is limited information about PFACs that integrate a transcultural, community centered focus. This project is designed for a large, health care organization in the Midwest which currently has nine PFACs. However, all of these councils are disease-diagnosis based and none serve across all departments (Peterson, 2010).

This project is important because a PFAC dedicated to culturally diverse patients and families will serve as a vital, sustainable bridge between the organization and the community it serves. It will enhance relationships between staff members and community members. Providing appropriate, cross-cultural health care is impossible without partnerships based on trusting, respectful, and responsible relationships among health care providers and patients, their families and communities (Lipson & Dibble, 2005). It is important and timely that nurses should take the lead in designing and implementing a transcultural PFAC. The emphasis of the nursing profession on caring and trust is rewarded as it is consistently rated the most trusted profession in the United States (Gallup Poll, 2004). The public clearly values the professional caring nurses provide. Madeleine Leininger (1991) has written that "caring is the 'heart and soul' of nursing and what people seek most from professional nurses and in health care services" (p. 5). Subsequently, nursing is ideally positioned to facilitate the

collaborative, trusting relationships needed to implement a transcultural PFAC effectively.

The project will contribute to advancing patient-and family-centered care at a major healthcare institution and provide an ideal opportunity for nursing leadership to have impact. Nurses with advanced practice are in a unique role to provide patient and family centered care (Reid Ponte & Peterson, 2008). Peterson (2009) suggested that mechanisms which promote nurse engagement in quality improvement activities improve PFCC climate and culture in hospitals. Indeed, nursing has the opportunity to impact and shape healthcare delivery at the organizational level through engagement of patient and family voices in a culturally competent way. Furthermore, there is significant potential for expanding transcultural knowledge in caring patterns, expressions and meanings.

The PFAC will potentiate a world of possibilities for organizational improvement in the patient experience. It will bolster the organization's efforts to develop a culture of quality and safety. It may unite diversity efforts within this large healthcare organization as it will serve as resource for all departments and units. In addition, the PFAC will provide the infrastructure to systematically connect to voices of diversity. The collaboration and sharing will illuminate a better understanding of the organizational strengths and opportunities for growth. Lastly, it is an initiative that has potential to improve health care outcomes, particularly in quality, safety and health literacy.

### **Theoretical Grounding**

Madeleine Leininger's (1991; 1997; 2002) revolutionary work in nursing theory fundamentally adjusted care to the expectations and needs of patients and families.

Culture Care Theory reconciles the scientific and humanistic imperatives and values in health care while preserving the wholeness and health of patients as they struggle with disruptions in health. Leininger developed the idea of integrating appropriate cultural practices and preferences in the patient care experience to improve satisfaction and healthcare outcomes. Her theory encourages creative approaches to ensure that patient's care needs are met in a meaningful and helpful manner.

Patient-family centered care necessitates that nurses acquire comprehensive knowledge about the patient in order to provide care that is compatible with their culture. This approach goes beyond physical and mental needs, to discover more about their everyday experiences, their aspirations and concerns, and the relationships that are important to them. In other words, care providers should value the personhood and see beyond the medical diagnosis and illness. This process encourages uncovering what makes a particular individual unique and what connects them to others. It is based in a partnership model.

The nurse partners with clients, families, groups, communities and institutions to provide holistic care enabling health (Leininger, 1991). This partnership described by Leininger decades ago is a testament to her forward, revolutionary thinking. Partnership alludes to an equal grounding between nurse and patient. Nurses act as facilitators of health versus dominant providers in an intervention based model of care. Her model is based in partnership and respect for *emic* knowledge of health and healing. The *emic* perspective carries the voices of patients and families, communities, and "folk" wisdom or ancestral knowledge. *Emic* perspectives offer a wealth of knowledge and can be useful to guide organizational change. According to Leininger

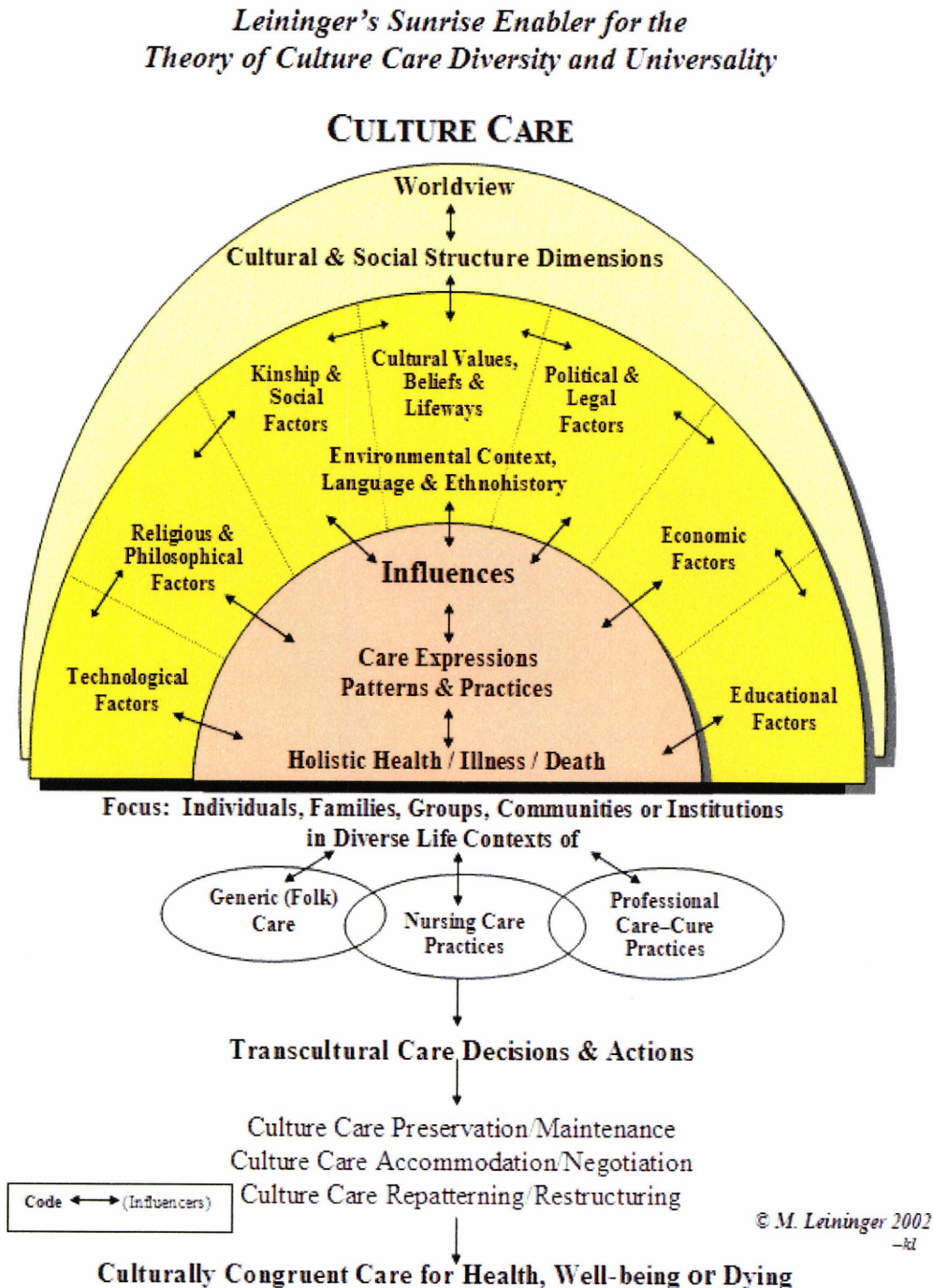
(1991), the nurse must have knowledge of culture and care values in order to provide therapeutic care and to prevent nontherapeutic conflicts, stresses and imposition practices. Leininger (1997) contends that the blending of *emic* folk knowledge with professional *etic* knowledge is essential to provide culturally congruent care. A patient family advisory council is an ideal fit to the blending of perspectives between family advisors and professional healthcare staff. The partnership between “folk” wisdom and professional wisdom mirrors the structure of a PFAC. These knowledge sources are in equal standing as reflected in the model implying a true partnership for knowledge growth.

Leininger’s *Sunrise Enabler to Discover Culture Care* in Figure 1.1 depicts a cognitive, holistic guide of the many factors and perspectives which influence a person’s health and healing in a cultural context. It promotes a relational approach to care. The predominance of dual direction arrows implies an underlying assumption of a complexity of influences which are accounted for in her model (see Figure 1). Professional nursing can illuminate the care meanings and expressions which explain health among individuals, families, groups and communities. Transcultural nurses understand the complexity of the diverse meanings and expressions of care found in diverse human communities. Subsequently, nursing is poised to be the ideal facilitator to bridge the patient and family perspective with professional healthcare system through the PFAC structure.

The *Sunrise Enabler* pronounces three action modes of preservation, negotiation and repatterning as key components to the provision of culturally ethical and sensitive care. This process underscores an openness to explore cultural meanings and



Figure 1.1: Madeline Leininger's Sunrise Enabler utilized as a guide.





differences with patient, family and community and a willingness to incorporate practices within the healthcare environment.

### **Storytelling, Ritual & Dialogue: Indigenous Ways of Being and Knowing**

Transcultural knowledge has been passed through generations across cultures of the world (Leininger, 1991). Nursing as both art and science has its earliest beginnings in ancestral healing and caring practices. The wisdom of Indigenous healing traditions can be maintained in the implementation process of a transcultural PFAC and in accordance with Leininger's culture care action modalities of preservation, accommodation and repatterning. Storytelling is a culturally sensitive tool to promote group relationship connection, compassion and care. "Stories are the fundamental dimension of the human experience" (Liehr & Smith, 2008, p. 205). Storytelling is a culturally comfortable, meaningful way to engage culturally diverse patients and families in improving the care experience. It is

In addition to storytelling, the use of rituals and respectful dialogue will provide a culturally tailored methodology package for the implementation plan of a transcultural PFAC. Rituals fit well with a holistic view of health and healing and provide a tangible means to restore greater compassion and caring into the modern healthcare system. Rituals offer a way to connect ancient healing wisdom to modern day healing systems. A group's collective identity can be deepened and maintained through the use of ritual in revealing group values and shared meanings (Laird, 1984). Rituals can affirm and strengthen connections to family, culture and community (Helsel, Mochel, & Bauer, 2004). Dialogue shaped by compassion and authentic listening will facilitate the creation of a culturally safe and comfortable environment conducive to engage the

voices of culturally diverse patients and families in a meaningful and sustainable manner.

### **Summary**

There are several compelling reasons to develop care models which provide family-centered, culturally congruent care. As discussed, these reasons include the nation's growing cultural diversity, the persistence of healthcare inequities that continue to disproportionately affect ethnic minorities, and multiple legislative, regulatory and accreditation mandates. The creation of patient family advisory councils is one of the ways that health care organizations have tried to make health care more effective and culturally relevant.

Implementation of a transcultural patient family advisory council is a concrete step towards ensuring that the voices of patients and families are systematically engaged when care decisions and actions are required. This project supports an effective transcultural way to engage culturally diverse patients and families in the implementation plan through the *emic* expressions of storytelling, ritual and dialogue. Chapter two will explore relevant literature that supports an Indigenous wisdom-based approach to the design and implementation of a transcultural PFAC at a large Midwestern health care organization.

## Chapter Two

### Literature Review

*To be a person is to have a story to tell.*

- Isak Dinesen

While the patient-and family-centered care (PFCC) approach is fast becoming the national standard for health care organizations, limited data exists related to the direct impact of patient family advisory councils (PFACs) on quality and safety outcomes. Furthermore, limited data exists related to the direct impact of PFACs in addressing healthcare disparities. PFACs have significantly improved patient satisfaction, patient adherence to treatment regimens, and increased staff satisfaction (Meyers, 2008). PFACs are considered so highly effective to improve the patient care experience that Massachusetts passed legislation that requires every medical center within the state to establish one by 2010 (Dreyer, 2009). This legislation is a testament to the low cost, high quality composition of advisory councils. PFACs resonate with the core values of healthcare organizations' missions and values to support the needs of patients. Furthermore, PFACs reflect the core principles of PFCC which are dignity and respect, information sharing, participation and collaboration (Institute of Patient-and Family-Centered Care, 2011).

The core principles of PFCC are consistent with a culturally competent care model. Cultural competence is an important feature of providing quality care to diverse populations (Betancourt, 2006). Interestingly, the movement to advance family centered care and cultural competence in healthcare have evolved along parallel tracks in the research literature (Arrango & McPherson, 2005; Beach, Soha, & Cooper, 2006; Goode & Jones, 2006; Ngo—Metzger et al., 2006). Indeed, PFCC and cultural

competence are integrally linked (Goode et al., 2009). Studies show that family centered and culturally competent care which values diversity improves quality, safety and satisfaction (Anderson et al., 2007; Beach, Saha & Cooper, 2006; Chernoff, Ireys, DeVet & Kim, 2006; Meyers, 2008, Ngui & Flores, 2006). Patient and family centered care *is* culturally competent and research supports the notion that they are interrelated and synergistic.

### **Indigenous Ways of Expressing Care: Storytelling**

There is growing awareness that storytelling is a means to achieve what is unique to nursing. Storytelling facilitates the understanding of cultural expression. Margarete Sandelowski (1991) aptly stated, “by incorporating culturally familiar narrative models, stories provide a sense of connection to other people” (p. 26). Indeed, stories provide a sense of connection between and among life events. Human lives echo in stories demanding our attention to listen. They are shaped by cultural expressions, preferences, and values. Telling a good story has been described as the “oldest tool of influence in human history” (Simmons, 2006, p. xix). Anyone with experience as a human being can tap into this source of influence and connection to drive positive change in their organization.

Storytelling is an effective methodology to advance patient centered care. Clark, Hanson and Ross (2003) explored the views of elders, their family and practitioners regarding their participation in life story work in a hospital transitional care unit. This small scale study found that using a biographical approach encouraged practitioners to see the person behind the patient, build and strengthen relationships with patients and their families and to understand individuals more fully for care planning. Kirkpatrick,

Ford and Castelloe (1997) concurred that storytelling promotes problem solving and has the ability to motivate, inspire, teach or enhance the human sensitivity skills needed by healthcare providers. Furthermore, stories promote the internalization of education through capturing the spirit surrounding the facts. In patient safety, storytelling enhances the transfer of knowledge and bridges the gap between knowledge acquisition and translation into practice (Rabinowitz & Mazzapica, 2010, p. 486). The Agency for Healthcare Research and Quality (2006) offers a story-based program to enhance organizational performance in patient safety, named Team STEPPS. This evidence based program is framed with powerful stories of medical harm. It is based on the work of Annette Simmons (2006) and the six types of stories that inspire listeners and guide the teaching process to inspire real change. Rabinowitz and Mazzapica (2010) utilized this program to create effective change improving patient safety and process improvement in a large health system, specifically documenting staff behavioral changes, and decrease in ventilator associated pneumonias and unplanned extubations in intensive care.

Storytelling can be an essential ingredient to inspire and drive organizational safety and quality improvement strategies. Quaid, Thao, and Denham (2010) reviewed storytelling best practices and conducted a video story study which directly surveyed hospital safety leaders at 675 hospitals. They found that over 90% strongly recommended the video to be shown to staff as a tool to reduce harm to patients. This study supports how storytelling based methodologies are influential tools in the healthcare quality and safety movement to inspire meaningful change.

The healthcare industry can learn from other industries to drive change that can save lives. The media industry commonly engages audiences through powerful stories. In 2010, the patient safety documentary, *Chasing Zero: Winning the War on Healthcare Harm*, was released and given to nationwide hospital CEOs (Listiak). It featured the actor and patient safety advocate Dennis Quaid and his compelling story of medical harm to his twin children (Listiak, 2010). This documentary's objective was to share stories to inspire the audience to overcome challenges and act in their own communities and hospitals with safe practices endorsed by the National Quality Forum. It translated the statistics into meaningful stories to drive change. Another example of educational media using stories is the nationally recognized *RACE: Are We So Different?* interactive exhibit (The American Anthropological Association, 2010) which explores the complex story of race through history, science and the lived experience. The project followed a similar formula using stories to illicit inner voice to develop empathy and connection to the educational content. Both media projects support the notion that storytelling is vital tool to support individual, community and organizational change.

### **Storytelling and Healthcare Disparities**

Emerging evidence suggests that storytelling may offer a unique opportunity to promote evidence based choices in a culturally appropriate context. In 2011, *Annals of Internal Medicine* published a randomized trial testing an interactive storytelling intervention on 230 African Americans with hypertension (Houston et al.). The researchers concluded that the storytelling intervention produced substantial and significant improvements in blood pressure for patients with baseline uncontrolled hypertension. This study supports the premise that storytelling can be part of a

culturally tailored education and clinical treatment plan. Many cultures have rich storytelling traditions. Therefore, culturally sensitive messages conveyed through the medium of storytelling will likely impress more meaning and support the notion of storytelling as an important tool in health promotion in vulnerable populations. It should be preserved and maintained for culturally congruent care as Leininger's theoretical guidance supports.

Storytelling is a culturally effective approach to promoting health in underserved ethnic minority populations. Larkey, Lopez, Minnal and Gonzalez (2009) conducted a randomized pilot study evaluating the potential of storytelling as a culturally aligned narrative method to promote colorectal cancer prevention and screening compared to a risk tool based intervention amongst low socioeconomic status Latina women. This study concluded that the story based approach may be effective for changing risk related behavior intentions. The storytelling approach for health promotion and teaching is well supported in the literature particularly in cancer prevention (Hodge, Pasqua & Marquez, 2002; Larkey & Gonzalez, 2007; Williams-Brown, Baldwin, & Bakos, 2002).

Storytelling provides a culturally relevant approach to gathering information about what matters most to patients and families. Intentional dialogue is a central concept within the nurse-patient relationship and the essence of story theory by nursing theorists, Liehr and Smith (2008). Millender (2011) illustrated how using a story based approach was effectively used at the bedside of a Guatemalan Mayan patient to develop a culturally sensitive plan of care. She highlighted the use of authentic communication and intentional dialogue to bring voice to the patient's and family's concerns and assist in finding meaningful, culturally competent health solutions. This

case study supports the notion of using storytelling to deliver more culturally responsive care. Coming to know another's health story is a first step to creating a bridge between *emic* and *etic* perspectives. Because nurses are front-line providers of care in hospital and community settings, they are uniquely positioned to obtain stories that can help uncover and explain similarities and differences in cultures that affect health disparities. A transcultural patient family advisory council is a suitable home for storytelling thereby providing an additional structure to intentionally uncover what matters most to culturally diverse patients and families. This open process facilitates Leiningers action modes of preservation, negotiation and repatterning for culturally congruent care.

Further research addressing health care disparities amongst marginalized communities underscores the importance of storytelling to help bridge the gap. Stories shape thinking about health and healthcare. Hutson, Dorgan, Phillips and Behringer (2007) used a community-based participatory approach to review regional findings about cancer disparities with grassroots community leaders in Appalachia to identify perspectives about what makes the cancer experience unique. Cancer storytelling was one of the four major themes which emerged influencing perception of health, health care and cancer. The mountains metaphorically "hold in" culturally bound stories about the ubiquitous nature of cancer and especially the causes of cancer (Hutson et al. 2007, p. 1135). This research honors the integrity and knowledge of community members. It underscores how one can learn a great deal about how to solve health care problems through embracing a relational approach and *emic* knowledge.



### **Relational Practice, Indigenous Wisdom and Healing**

Caring patterns, expressions, and meanings have been passed through generations across cultures of the world through oral traditions. Nursing as both art and science has its earliest beginnings in ancestral healing and caring practices. Relational practice is a human process of respectful, compassionate, and authentically interested inquiry into another (and one's own) experiences (Doane & Varcoe, 2005, p. 200). A connection is born from desire and willingness, not the possession of expert knowledge. Nash (2008) stated that "helping individuals recognize their power is grounded in the power of connecting, interacting and interrelating" (p. 206). Therefore, expert practice goes beyond concrete knowledge accumulation to a stance of wisdom. This kind of practice reconnects the healer with ancient intelligence and intuitive ways of knowing. Respect, integrity and compassion can then be restored into the healing relationship.

The use of storytelling, rituals, and intentional dialogue are culturally competent ways to develop relational practice to advance culturally congruent care in healthcare practice models. These three ways offer a way to preserve, accommodate and repattern healthcare delivery to connect to its' vocational roots grounded in holistic healing and Indigenous healing traditions. Holistic nursing practice mandates developing expertise in the skills of storytelling and dialogue, skills that help the nurse to recapture what is essentially human in health care (Sandelowski, 1994). "Through caring relationships, people have the opportunity to experience the power of human connections in the healing process" (Doane & Varcoe, 2005, p. 178).

## Ritual

Indigenous wisdom supports the use of ritual to create better communication and connection. Rituals allow us to connect with one another and build community.

Sobonfu Some (1997), *West African voice in spirituality and healing*, describes ritual as “like a meal where everybody brings an ingredient....it has to start with the setting of the intention and with a group of committed people who want the greatest good to happen” (p.45). This wisdom of the importance of ritual can support the implementation process of a transcultural PFAC. Ritual use will be explicated in chapter three.

The literature supports rituals as an integral part of practice and research. Leininger’s *Sunrise Enabler* encourages the discovery and understanding of care practices to facilitate better health and wellbeing in patients, families and communities. Rituals complement holistic health care and have a great deal of potency for healing. They allow for a deeper connection to the shared human experience. Rituals have been shown to reduce anxiety and depression, reduce feelings of helplessness, allow for demonstrations of family and community support, encourage self acceptance and compassion for oneself, and may directly evoke a higher power or healing source (Achterberg, Dossey, & Kokmeier, 1994; Anastasi & Newberg, 2008; Cole, 2003; Koss-Chiolini, 2005). Rituals are an integral part of the healing journey and relevant to modern nursing practice as an expression of caring and compassion. Rituals support the meaning and purpose of nursing actions and are in need of further research and exploration (Philpin, 2002).

Rituals support relationships and health. Wu and Barker (2008) conducted a qualitative study examining the cultural basis of mealtime experiences among ethnic

long term care residents, family and staff members. This study found that the biomedical, individualized food service and mealtime caregiving practices stripped food of its meaning as a social, shared mealtime experience with family. This study underscores the importance of food sharing ritual practices amongst cultural groups to promote cultural comfort and the role of caregivers to gain transcultural understanding of ethnic cultural contexts.

### **Effective Dialogue**

The notion of “talk” is very important to Indigenous communities. This wisdom is reflected in Buddhist philosophy as stated by the Dalai Lama:

“Warfare failed to solve our problems in the last century, so this century should be a century of dialogue. Every problem must be solved through talks, understanding of others’ interests, others’ rights. (Dalai Lama Pays, 2008, p. 1)

Recent research supports a wisdom-based dialogue approach in conducting health research in a culturally informed way. Frequently used in the American Indian community and proven to be a valuable tool in health research, a Talking Circle is a method used by a group to discuss a topic in an egalitarian and nonconfrontational manner. Using community-based participatory research, a modified Talking Circle format was developed for engaging tribal leaders in an American Indian Healthy Eating Project in North Carolina (Fleischacker, Vu, Ries, & McPhail, 2011). This culturally informed approach enabled researchers to garner project support from seven tribes, as well as insights on developing planning and policy strategies to improve access to healthy eating within each of the participating communities. Another research study by Becker, Affonso and Beard (2006) used a talking circle format to explore the cultural

meanings of cancer among American Indian women and their experiential view of cancer screening. This talking circle approach has been used in non-American Indian populations to address health disparities. Ford (2007) studied the perceptions of personal and environmental factors affecting hypertension with African Americans in the rural South.

The notion of “talk” is further supported by research examining community perspectives of the healthcare experience. Qualities associated with a favorable healthcare experience included effective verbal and nonverbal communication, feeling valued and understood, and access to healthcare services and investment in community programs to improve health literacy (Carroll, Epstein, Fiscella, Gipson, Volpe, & Jean-Pierre, 2007). Studies support patient-centered communication can improve shared decision-making about appropriate preventative screening, alleviate anxiety and improve trust (Epstein, Alper & Quill 2004; Epstein, Franks, Shields, Meldrum, Miller, & Campbell, 2005). Literature supports that effective communication and language competency are cornerstones to culturally appropriate and respectful care (Betancourt, 2004; Christensen, 2004).

Patient-centered, effective cross-cultural communication is essential to reaching patients with low health literacy. Low-health literacy, cultural barriers, and limited English proficiency have been coined the “triple threat” to effective health communication by the Joint Commission (2010). Singleton and Krause (2009) support the interrelatedness of how culture and language can influence the patient experience relevant to health literacy. Nurses are in the ideal position to facilitate the interconnections between patient culture, language and health literacy in order to

improve health outcomes for culturally diverse patients. Nurses must create a shame-free environment, foster respectful and caring atmosphere in which open dialogue is encouraged. Empathy is a critical element of this type of supportive communication (Spero, 2011).

Low health literacy is solidly linked to poorer health outcomes with higher costs disproportionately affecting lower socioeconomic and minority groups (USDHHS, 2010). In the absence of language barriers, there are many culturally based health values, beliefs and preferences of native-born patients that may be missed. Research shows that native-born minority patients may have less experience with healthcare because historically healthcare opportunities have been unavailable to them (Eiser & Glenn, 2007). Insurance status and experiences of discrimination and stigma in the healthcare system creates a persistent mistrust of healthcare institutions and clinicians (Smedley, Stith & Nelson, 2003). Rural dwelling Americans is another native-born population for whom culture and health literacy interact. Rural populations experience more negative health outcomes. In a study by Giger and Davidhizar (2008), it was found that familialism, high context communication, a connection between health and religious beliefs, use of folk remedies, and distrust of outsiders, including health care providers, significantly impacted health and health-related communication. This study supports how effective transcultural dialogue is vital in efforts designed to improve the health of culturally diverse populations.

### **Indigenous Wisdom in Culturally Safe Research**

Relationships matter and they are a gateway to valuable knowledge and empowerment in transcultural research with vulnerable populations. Subordinated

groups tend to know a great deal about mainstream, dominant culture, but the converse is seldom true (Hall, Stevens, & Meleis, 1994). De and Richardson (2008) argue for a cultural safety approach in health care in the context of a power gradient in relationships. The approach is based on a broad definition of culture and on the provider's analysis of their cultural self and their impact on therapeutic encounters. Subsequently, the voice of the service user is given a great deal of weight and authority as they are the judge of whether the professional relationship feels culturally safe. Cultural safety is used widely in Australia, New Zealand and Canada as a theoretical framework enabling more effective relationships in nursing practice and research. It complements Leininger's Culture Care Theory and is particularly suited to support working with culturally diverse and vulnerable populations. There needs to be recognition and awareness that a power gradient exists and culture is not synonymous with ethnicity (De & Richardson, 2008). It is crucial that health care providers recognize the variability and individuality to which people vary in cultural groups and carry sensitivity and awareness of their own cultural selves and the impact on others. Moreover, in the context of this project at a large, health care organization, it is crucial to understand the impact that the system has on the patients and families.

Indigenous nurse researcher, Ann McClelland (2011) used an Indigenous methodology in a university study examining the experience of education for Maori nursing students in New Zealand. A Kaupapa Maori methodology was used as a lens for the research. This approach enabled the participants and researcher to develop a culturally safe process in the form of a metaphorical *whanau* (family). The findings showed that Maori students formed modern whanau groups which enabled them to

succeed in their nursing program. The methodology also incorporated Maori constructs of elder mentorship, *whakawhanaungatanga* (connectedness), networking, and participation.

De and Richardson (2008) argue that achieving cultural safety in nursing practice begins with a self-desensitizing cultural awareness, then cultural sensitivity (understanding one's impact on others) and finally to the outcome of cultural safety (to be defined by the service user). Disenfranchised people and disempowered people can find it difficult to communicate with someone whom they perceive as having more power and authority. Discerning the power gradient and taking action to rectify it is essential to achieve safe, individualized, quality care. A transcultural PFAC levels the playing field in terms of placing patients and families on more equal footing with healthcare staff to engage in honest and productive communication. Allowing a stronger voice for ethnic minorities and diverse individuals in care planning and decision making can be a source of empowerment and contribute to a more culturally safe environment.

### **Nursing Theory Support**

Surprisingly, there is a void of research data and literature to specifically and directly address Leininger's theory and PFACs or PFCC directly. However, Leininger's *Sunrise Enabler to Discover Culture Care* (2002) provides an ideal guide to support the development of a practice model for the design and implementation of a transcultural PFAC for the reasons described in chapter one. The highest quality patient care is provided with compassion and trust to meet the needs of the patient. Leininger (1991; 1997; 2002) supports the virtue of compassion when she describes care as a universal need and care that is culturally congruent. Interestingly, the virtue of compassion is

absent from nursing scholarship and the practicalities related to contemporary care delivery models (Burnell, 2009). The virtue and practice of compassion allows the caregiver to enter into the suffering and adversity of patient experiences and establish connection. Compassion is lifted as an important fundamental concept to shape and drive the proposed practice model described in chapter three.

### **Summary**

The literature review supports the notion that the integration of storytelling, ritual and intentional dialogue is both culturally appropriate and effective in working with culturally diverse populations. Using an indigenous-wisdom base approach in the implementation process of a transcultural PFAC is a key step to operationalizing patient-centered care in healthcare organizations.

Patient- and family-centered care assures the health and well being of patients and families through a respectful family-professional partnership. The nurse-healer not only creates an environment in which patients feel comfortable to share stories but also partners with them to establish meaning from the process. Nursing is ideally positioned to facilitate the blending of knowledge and perspectives in the form of a transcultural patient family advisory council. The next chapter will describe a practice model informed by Indigenous wisdom and Leininger's (2002) Culture Care Theory. The key concepts of compassion and connection will be integrated into the model.



## Chapter Three

### Development of the Practice Model

*I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.*

- Maya Angelou

The voice of the patient is essential to advance towards creating an ideal patient experience in a complex healthcare organization. This chapter describes the development of a practice model which supports driving healthcare change through the implementation of a transcultural Patient Family Advisory Council (PFAC). The Bridge to One World model (see Figure 3.2, p. 39) supports the voice of culturally diverse patients and families in the design and implementation of a transcultural PFAC. Indigenous ways of relating to others—storytelling, ritual, and dialogue—are integral components of the implementation process. These ways of relating have been selected because they have the power to engage culturally diverse patients and families and to illuminate the meaning and expression of care and caring transculturally. As such, cultural wisdom is encouraged to emerge and to play a more prominent role in supporting the planning and delivery of care at a large, urban healthcare organization.

A primary assumption of the PFAC model is that the family plays a vital role in the health and wellbeing of patients. The core concepts of patient-and family-centered care are dignity and respect, information sharing, participation and collaboration (Institute of Patient-and Family-Centered Care, 2011). These concepts complement the One World model's central concepts of relationship, partnership, connection and compassion. Health care providers are directed to listen to and honor patient and family perspectives and choices. This allows for patient and family knowledge, values, beliefs

and cultural backgrounds to be incorporated into care planning and decision making in a respectful, ethical manner.

A second assumption of the One World model is that culturally congruent care is fundamental to creating the ideal patient experience. Guided by Leininger's (2006) *Sunrise Enabler*, the One World model is centered around a framework of partnership and a holistic comprehensive approach. The *Sunrise Enabler* explicates a culturally competent way of guiding health care decision making. Leininger's (1991; 1997; 2002) three action modes of culture care preservation, accommodation and repatterning inspire culturally effective care decisions and actions. As such, the theory of Culture Care Diversity and Universality and the *Sunrise Enabler* establishes an underlying openness to explore cultural meanings and differences and a willingness to integrate this wisdom into the healthcare system. A respectful partnership based in compassionate, relational practice is encouraged. In other words, the One World model is an approach to knowledge development and understanding as well as the provision of service in a relational manner versus the provision of a service in a disease oriented or problem focused manner dominating most healthcare settings. Leininger's action modes are an essential part of creating the ideal patient experience.

A last assumption of the One World model is that every patient deserves the best possible compassionate care. The Charter for Compassion (2011) is a document designed to transcend global religious differences. Supported by religious thinkers from many traditions, The Charter for Compassion states that the principle of compassion lies at the heart of all religious, spiritual, and ethical traditions calling us to treat all others as we wish to be treated ourselves and compelling us to alleviate the suffering of

others and treat every single human being with absolute justice, equity and respect. The rationale for universal compassion is at the heart of the ancient wisdom of Buddhism. True compassion is not just an emotional response but a firm commitment founded on reason (Dalai Lama & Cutler, 1998). This broad view of compassion as a responsibility to every member of the human family is a vital fundamental concept to One World. It is an essential part of the progress towards the ideal patient experience. In the critical moments and challenges of life, we need an expanded conceptualization of “vital signs” for patients and families. Adoption of an Indigenous wisdom-based model to create a compassionate, healing environment will improve the patient experience for diverse populations and all persons seeking care at the organization.

### **Diversity and Indigenous Wisdom**

In developing the One World model, a diversity-related image was chosen early in the planning process. This world image in Figure 2.1 became part of a flyer utilized to support recruitment of members and advertise the formation of this new group at a large, Midwestern healthcare organization. As there were nine other department-based and disease-oriented PFACs previously established at this organization, the world image contributed to differentiating this model from other PFAC models and set the diversity-focused tone.

The world image reflects the symbolic conceptualization of the spirit of the transcultural PFAC. The planet Earth held up by a diverse group of hands symbolizes the interconnection of human beings in problem solving for our mutual benefit and the greater good. The interlaced hands further emphasize humanity’s interconnectedness.

Figure 3.1: World image used for symbolic conceptualization of the Transcultural PFAC supporting the major concepts of the Bridge to One World model.



The model is based on respectful partnership. Effective partnership depends on mutual respect and openness to learning from one another. The intersection of diverse voices strengthens the whole. This non-hierarchal approach creates a fuller sense of equity, personal commitment and connection to the group.

The world image in Figure 3.1 harmonizes well with Indigenous cultural wisdom. The classical South African humanist philosophy of *Ubuntu* is highly applicable to the spirit of the transcultural PFAC and patient family centered care approach. Desmond Tutu (1999) explained Ubuntu as follows:

One of the sayings in our country is Ubuntu - the essence of being human.

Ubuntu speaks particularly about the fact that you can't exist as a human being in

isolation. It speaks about our interconnectedness. You can't be human all by yourself...We think of ourselves far too frequently as just individuals, separated from one another, whereas you are connected and what you do affects the whole World. When you do well, it spreads out; it is for the whole of humanity. (p. 32)

The Indigenous wisdom of Ubuntu is relevant to creating a group dedicated to the voice of patients and families and improvement of the patient care experience. It underscores the key concepts of compassion and connection as it relates to the practice model.

Native American Indigenous wisdom also underscores concepts of compassion and connection and reflects an inherent belief that everything and everyone is connected. *Mitakuye Oyasin*, a Lakota prayer, translates to *We are all related*. It reflects this inherent belief in the connection of all life on Earth while resonating a profound respect for the sacredness of each person's individual path and contribution. This indigenous wisdom creates an energy of awareness based in harmony and connection. It inspired the selection of the symbolic image for the council. It supports the fundamental assumption of the One World model that every person deserves the best possible compassionate care.

### **Description of Bridge to One World Model**

At the center of the Bridge to One World model (Figure 3.2) is the bridge which signifies the central elements of partnership, relationship and connection shaped by the practice and compassion. The bridge connects the *emic* voice or knowledge of patients and families to the *etic* voice or professional staff knowledge/caregivers. The troubled water beneath the bridge signifies the cultural and social structure dimensions which include the health care environment and the people within it. More specifically,

dimensions of language, cultural values, beliefs and lifeways, religious and philosophical factors and economic factors are part of this scene. This “troubled waters” are confusing and chaotic to navigate and understand, but the bridge allows for the opportunity to partner for “smoother waters” or understanding signified by sunshine. This process advances the healthcare organization towards the ideal patient experience. Leininger’s (2002) action modes of care preservation, negotiation and restructuring are the “paintbrushes” caregivers use to paint a new picture for redesigning healthcare.

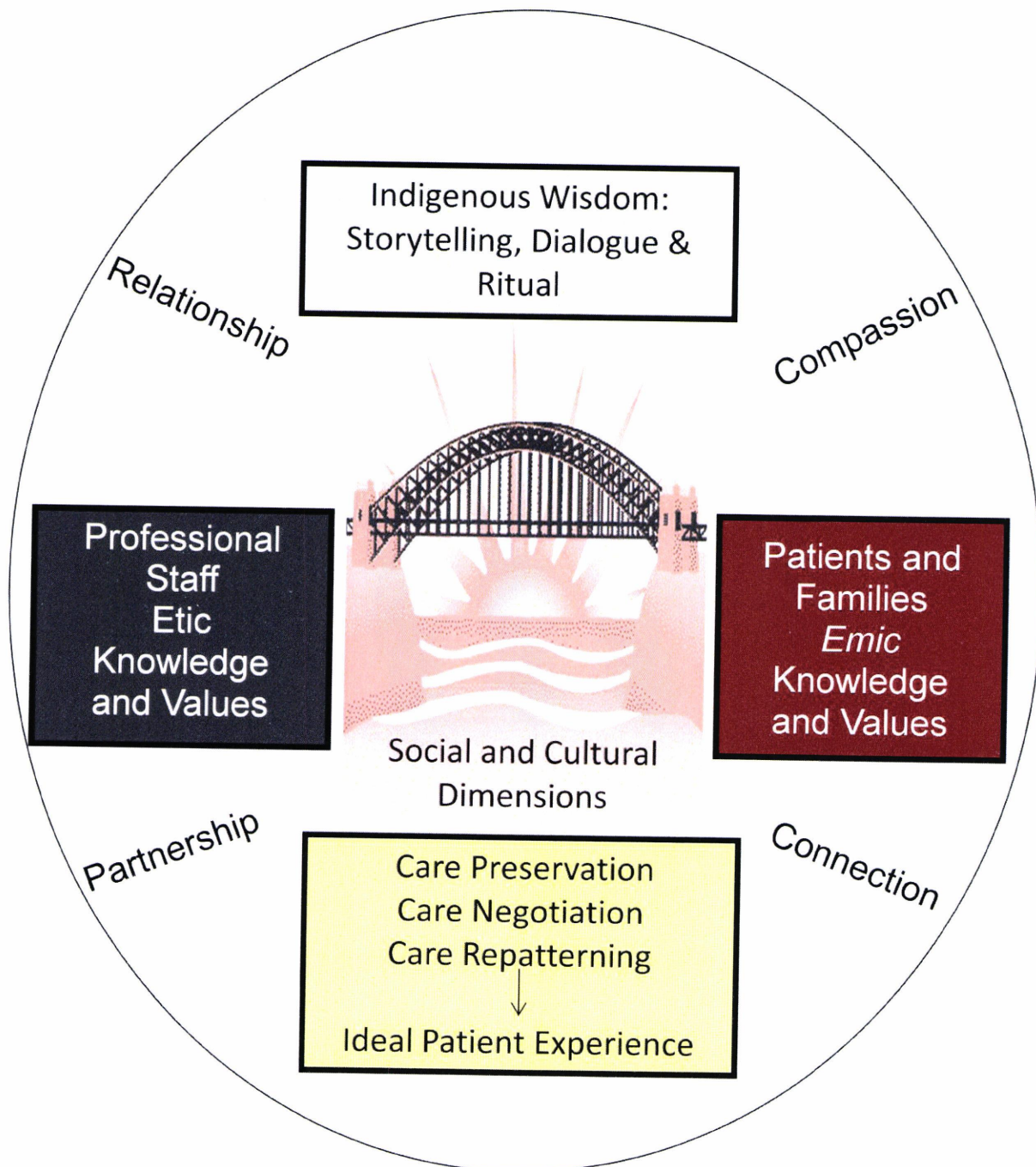
One World is inspired by the medicine wheel and the four cardinal directions found in Native American spirituality. Indigenous peoples of North America use the sacred hoop or medicine wheel in many variations as a symbol of the never-ending cycle of life. This sacred architectural circular shape has no beginning and no end, emphasizing a nonlinear nature and view of health and healing. One World displays four colors in text boxes inspired by the four cardinal directions in the cosmology of Indigenous peoples of North America.

In the One World Model (Figure 3.2) white is north, for wisdom and cleansing gained through stories. Red, for east, represents enlightenment, vision and insight. Yellow, for south, sees a sun the strongest when facing this direction which stands for the peak of life, warmth, understanding and ability. Black, for the west, symbolizes power and structure. The bridge is at the center signifying that the relational connection which the advisory council model is based upon. The bridge connection occupies the heart of the care model and essential for driving change. The four central concepts of



Figure 3.2: The Bridge to One World Practice Model

# A Bridge to One World



compassion, connection, relationship and partnership create a wheel spoke effect.

They are fundamental driving forces shaping the implementation plan.

## **Background**

The original idea for a PFAC dedicated to the needs of culturally diverse patients and families was generated by the leadership of a multidisciplinary Transcultural Patient Care Subcommittee (TPCS) group at the healthcare organization. Based on support from this host committee (TPCS), a dialogue-based networking model was used to seek support from senior level leadership at the organization and staff members interested in the needs of culturally diverse patients and families. An elevator speech was developed to share the vision and purpose of this project to propose its' value to prospective supporters. A physician leader from primary care was carefully selected and asked to support the group in order to ensure success at a physician-led organization. This physician leader had a diverse ethnic background and a professional background promoting diversity-related initiatives.

## **Design and Implementation: A *Wisdom*-based approach**

A network-based invitational strategy was used for recruitment to the council. Typically, PFACs are formed by physician/provider referral. Due to the nature of the transcultural PFAC being culturally and community centered versus disease and diagnosed based, referrals were invited from a variety of nontraditional sources. These recruitment strategies and selection criteria were approved by the TPCS. The option of physician referral was available but an invitational strategy was preferred in order to find individuals with strong community connections, care experience at the organization, and an ability to engage in broad, systems thinking. Previously established community



relationships and connections facilitated and personalized this approach. Targeted organizations include the local adult education center, a local refugee service organization, and spiritual centers. Community leaders in community based healthcare organizations were also contacted to generate awareness. Internally, meetings were conducted with leadership and members of the international department and language department to build support, collaboration and garner ideas for recruitment of members.

The implementation plan embraced an adaptive strategy which incorporated a great deal of flexibility in recruitment. For example, nurse co-leaders opted to conduct the inaugural meeting before the full twelve patient-family advisors were recruited. This resulted from choosing to follow an idea inspired by the popular 1989 film, *Field of Dreams* message of "If you build it, [they] will come." After personal communications with another PFAC leader in the organization, we learned that one successful cardiology-based group had started with only one member in 2008 and had since grown to 17 (C. Smith, personal communication, March 4, 2011). The literature supported careful attention to the staff-family ratio at meetings of the council. It recommended having 1/3 staff and 2/3 patient-family advisors. It was decided to blur these boundaries and move slowly towards that goal and send a strong message of support early on in implementation by including as many staff supporters who wanted to attend. Organizational meetings were conducted with staff separately prior to the inaugural meeting to orient them to the model and the need for patient/family dominance of voice at the meetings.

**Culturally safe intragroup dialogue.** The nurse can infuse the three Indigenous ways of relating to others by a host of concrete and practical measures

during implementation. Authentic listening is central to the process of connection. It creates an atmosphere of openness and safety, which invites compassion and the sacred. Listening to the person's story is essential. Sharing stories honors a deep relational connection and a sense of mutual safety. Storytelling, as a relational approach, is better suited to inspire motivation for meaningful change as supported by the research literature in chapter two. Storytelling was the first agenda item at staff organizational meetings and the inaugural meeting of the PFAC.

Culturally safe dialogue is at the heart of effective strategies for group communication. Prior to the inaugural transcultural PFAC meeting with patients and families, there were organizational meetings held with interested staff supporters. Nurse co-leaders intentionally worked to create a different ambience to these meetings by prioritizing staff sharing through allotted time for the group to share their personal story in connection to culture and community. Cultural artifacts, ethnic foods and teas were provided and a circular seating arrangement was arranged. An emphasis on the personal connection was encouraged and sharing beyond professional backgrounds. The goal of this approach was to build group cohesion and connection at a relational level. It was the plan for a staff support network to result from this approach, with greater chance of a sustained commitment to the council. This diverse group of staff supporters came from many areas in the organization and diverse backgrounds. The enthusiasm was very encouraging and brought further momentum to the project leading up to the inaugural meeting.

**Establishing ritual.** Patients and families were given the opportunity to share what they liked most about a recent care experience at the organization and what could



have been done better. Subsequent meetings, occurring every other month, will sustain a substantial part of the 90 minute meeting in topic-based dialogue, talking circles, and open forum time. A talking circle methodology will be used for a portion of the meeting time dedicated to reflection and developing a shared vision for the council. The ritual of a shared dinner meal is a suitable time for open forum and relationship building.

An opening and closing ritual reflection will mark the beginning and ending each meeting. This will initially be led by the nurse facilitator and subsequently patient- family advisors would be invited to take turns leading the opening and closing reflections. Initially, the nurse facilitator designed a brief ritual to mark the intention of the group and develop a relational connection to compassion and care. For example, the end of the meeting would be marked with a closing reflective statement, such as “We are thankful for the opportunity to be together, and to work on making life and healthcare better for all in our world. We look forward to seeing each other again. May you and your family be healthy.” This can be followed by an opportunity for members to translate, adapt or add their own message to share with the group. Behind the words is the meaning and the intent that the group is doing something meaningful that is only possible by being together in that moment.

**Creating a culturally friendly environment.** A community clinic based setting for the inaugural meeting of the transcultural PFAC was chosen. Due to the intimidating nature of the main healthcare organization campus, it was strongly agreed upon that a community-based location would suit the council best. This choice facilitated a more comfortable setting to support the patient-family advisors. It sends a stronger message of support to community members and builds a stronger bridge as the One World model

explicates. The meeting space was carefully chosen to possess a circular, non-hierarchal arrangement of tables and chairs to facilitate an environment of equity. Group consensus would determine locations of future meetings with a planned emphasis on community based locations off the main medical campus. Meeting locations will likely involve rotation to diversify the experience and enhance educational opportunities for members.

In the quest to improve the patient experience in a large, healthcare organization, the proven power lies in a wisdom-based methodology. As research evidence and Indigenous wisdom support, a wisdom-based approach—storytelling, ritual and dialogue—is well suited to the design and implementation of a transcultural PFAC. Sharing stories conveys meaning and fuels action by caregivers to partner with families for a better healthcare experience for all. The next chapter will present plans for evaluating the effectiveness of the One World model in the implementation of the transcultural PFAC.

## Chapter Four

### Evaluation Plans

*A little reflection will show us that every belief, even the simplest and most fundamental goes beyond experience when regarded as a guide to our actions.*  
-William Kingdom Clifford

The Bridge to One World model for implementation of a transcultural Patient Family Advisory Council (PFAC) enters into uncharted territory as the literature demonstrated. As described in chapter two, there was a void in the literature review reporting the existence and outcomes of PFACs solely dedicated to serving the needs of culturally diverse patient populations. Moreover, there was no literature describing Indigenous wisdom-based approaches used to effectively engage culturally diverse patients and families in implementation. Therefore, it is of critical importance that the early efforts of the Bridge to One World practice model be supported by qualitative and quantitative data. In order to ensure sustainable interest and resource allocation from the organizational leadership, we must be able to articulate and share the council's measureable and perceived benefits. It is important to establish metrics for successful outcomes and to monitor the effect of potential improvements on healthcare disparities. Such efforts will bring healthcare closer to achieving national goals of reducing healthcare disparities (as cited in *Healthy People 2020*).

Wilson-Stronks and Mutha (2010) conducted a recent study to better understand what motivates hospital Chief Executive Officers (CEOs) to focus and commit resources to supporting the delivery of culturally competent care. They analyzed the interviews of sixty hospital CEOs and found that they most often embraced efforts that helped them achieve the organization's mission and priorities and/or meet the needs of a particular

patient population. Leaders noted that to meet patients' needs it was essential to understand their perspective of care. Some hospitals proactively elicited information from patients and communities through surveys, focus groups and interviews and used this information to design services. Others ways used to identify needs included reviewing community public health data and questioning hospital staff. The use of a transcultural PFAC which would offer a viable, sustainable source was not mentioned. Bridge to One World offers a meaningful way of engaging patient and families in ongoing dialogue to identify health needs and provide insight into planning, delivering and evaluating health services. Furthermore, this project offers a cost-effective resource to the health care organization and community to inform strategies to improve quality of care.

The One World model proposes an integrated plan to document, measure and share the impact of this PFAC on care delivery at this organization. This plan includes the triad of (1) broad communications strategy (2) inclusive staff engagement plan, and (3) an ongoing reflection process. A broad communications strategy will strengthen the council and maintain organizational and community interest in the group. For example, a Facebook page can be used to connect with other PFACs and augment the connection between the community and staff. Patient-family advisors and staff supporters can be connected to the page to broaden dialogue possibilities and disseminate the story and activities of the council. Other strategies for sharing the story of the council include collaboration with public affairs to advertise the council in appropriate venues. A poster could be shared at the annual quality conferences at the organization in May and October. This poster would be cooperatively developed with

the input from members of the council. Upon completion of one year of the council, an annual report of goals and accomplishments will be shared with internal organizational supporters and senior administrators emphasizing how this group supports the core value of the organization—*the needs of the patient come first*. Meeting minutes will be regularly distributed to a wide network of supporters, leadership, and interested department management to maintain connection and vitality throughout the year. The transcultural PFAC needs to be connected to the nine other organizational PFACs through networking with PFAC leadership, social media, and considering an annual recognition dinner and/or conference for 2012. Other possibilities include pursuing utilizing the organization's bedside education and entertainment system to share the story of the council. In the long term, grant application for the Picker Institute or Commonwealth Fund could be considered after outcome data has been collected. All of these strategies and plans require organizational leadership buy-in and support.

Due to a very high, positive staff interest and response in the early phases of planning, the PFAC adopted an open, inclusive staff engagement plan. Any staff member in the organization is encouraged to connect with the council. A large network of staff supporters enables greater connections to resources, agenda items and engagement opportunities. As patient-family advisors meeting every other month, it will be strongly considered for staff supporters to meet on the six opposite months for the purpose of planning and preparing for the council meetings and developing internal networking. Furthermore, meeting with senior diversity leadership is planned to pursue developing better plans to integrate staff in supporting the council as it moves forward. Nurse leadership has the opportunity to advocate for the patient-family advisors and the



populations in the community they represent. We can direct the passion for serving the under-represented and working towards best outcomes in the patient experience.

Reflection is critical exercise for the council to practice at the end of every meeting and on an annual basis. Members of the council need to time to reflect on what went well, what needs to change, and what could be done. This reflection time must be built into the group meetings and encouraged amongst patient-family advisors and staff supporters.

The rationale for obtaining data to support the design and implementation of the council in its' first year needs to be shared and discussed with council members. One possible plan for pursuing the establishment of data to support the existence and efforts of this transcultural PFAC is to place it on as one of the early agenda items for the council. The importance and meaning of the effort can then be discussed as a shared responsibility. A REDcap survey could be initiated. REDcap is free, secure web-based application supporting data capture. Five culturally appropriate questions could be developed for the survey which could then be sent via email or posted by a link to the Facebook. This could be repeated at intervals to establish some data in quality improvement.

Implementation and evaluation of a transcultural patient family advisory council is a concrete step towards ensuring that the voices of patients and families are systematically engaged in the pursuit of high-quality, compassionate healthcare delivery. The pursuit of data to support the council as a quality improvement initiative is essential to ensure longevity and sustain organizational support.

## Chapter Five

### Discussion

*This is the great new problem of mankind. We have inherited...a great 'world house' in which we have to live together—black and white, Easterner and Westerner, Gentile and Jew, Catholic and Protestant, Muslim and Hindu...Because we can never again live apart, we must learn somehow to live with each other in peace.....The stability of the large world house which is ours will involve a revolution of values to accompany the scientific and freedom revolutions engulfing the earth. We must rapidly begin to shift from a "thing"-oriented society to a "person"-oriented society.*

*-Martin Luther King*

Nurses are in ideal positions to collaborate in building healthier communities through relational leadership. Adoption of an Indigenous wisdom-based model to create a more compassionate, healing environment will improve the patient experience for diverse populations and all persons seeking care at the organization. The Bridge to One World model affirms the basic essence of Indigenous wisdom: compassion and connection. This essence is affirmed by American Muslim and interfaith champion, Eboo Patel. Patel (2007) advocates a path of building bridges of understanding in proactive cooperation which affirms the identity of the communities while emphasizing that the wellbeing of each depends on the health of the whole. Furthermore, he defines pluralism as an "intense commitment that is imprinted through action...It requires deliberate engagement with difference, outspoken loyalty to others, and proactive protection in the breach" (Patel, 2007, p. 19). Communities need to move beyond simple tolerance to a process of intentional dialogue and search for common ground. Building this type of bridge is a pathway to better knowledge and relationships with families and communities.

In order to better understand barriers to health in our communities, one possible future project that suits the mission and vision of the One World model well is the use of a participatory methodology called Photo Voice. Photo Voice or Photo Novella uses innovative participatory photography and digital storytelling methods to allow communities to have the opportunity to use photography to record their communities' strengths and challenges to promote dialogue and encourage action. The method allows communities to explore and share their *emic* perspectives and promote a deeper understanding of health phenomena that can inform interventions to improve health outcomes for minorities (Castleden, Gavin, & Huu-ay-aht First Nation, 2008). A recent review by Catalani and Minkler (2010) found that it can be used to enhance community engagement, improve understanding of community needs and assets, and increase individual empowerment in community health. It has been shown to be a powerful tool in eliciting the perceptions from marginalized groups. This methodology contextualizes minority health and articulate personal stories of illness and healing in an impactful way. It offers a vehicle for deeper reflection.

As this practice model is projected to effectively establish and nurture development of the transcultural PFAC, it is hoped that over time, the patient-family advisors will gradually progress to greater control in driving the activities and direction of the council. In early phases, the nurse co-leaders planned to encourage a "low-hanging fruit" project to encourage a sense of cooperation and accomplishment in partnership. More sophisticated partnership-based projects would be appropriate for later phases of council development.

### **Implications for Decreasing Health Inequities**

The limitation of this model is that this transcultural PFAC is most likely to engage the voices of community leaders versus the deeper marginalized community members with more limited English proficiency, health literacy, and social connections. With a wisdom-based model directing implementation, it is hoped that this PFAC will give birth to collaborative outreach projects which could then narrow the gap and deepen the contact with more marginalized voices.

Nursing leadership can be instrumental in sharing the story of the council. Presenting at national quality conferences, publishing data and outcomes is crucial so that other health care organizations can embrace the model and the void of data can begin to be filled. The transcultural PFAC provides direct, timely, sustainable feedback grounded in relationships. It shapes care, influences decisions about policies and provides feedback about services. It serves as a resource for the organization and community to problem solve, generate ideas and make resolutions. It serves as a bridge and open door to partnership and dialogue.

### **Personal Reflections and Conclusions**

Working with a supportive nursing colleague in this process has been of profound importance to me. My co-leader and fellow Augsburg graduate, Lisa Peterson, helped me to develop my leadership abilities and confidence and provided the necessary support to develop creative problem solving skills, share responsibilities, and generate ideas. Working at a very large organization with a complicated infrastructure, one needed to have help navigating and stepping into unknown areas this project involved. We recognized early on that we worked well together and needed each other to see this

project through implementation. We engaged so many areas and people in this project as it developed that it was essential to have reliable support which we found in each other.

This project was grounded in relationships. My personal volunteer and graduate school community experiences gave me the connections and awareness to navigate the community domain successfully and build on existing relationships to generate support. My internal organizational connections also served the project well. The importance of finding like-minded, committed individuals who carry passion and interest in promoting diversity was pivotal to develop momentum and sustainability. It never ceases to amaze me the amount of enthusiasm and desire for positive change that is harnessed with dedicated leadership. This project *felt* right to me and it culminated my interests in working to provide a better patient experience for diverse patients and families. Diversity is part of the solution to improve care for all patients.

There will be continued challenges as this project grows and develops. First, there is the challenge of maintaining momentum. Projects can carry a life span and we want this transcultural PFAC to experience longevity as it is designed to do. Our role as co-leaders is very heavy in the early phase but it is our goal to cultivate intra-group leadership amongst our patient and family advisors and our supporters to nurture a future where our role wanes. We want our patient-family advisors to eventually be in the driver's seat. We can then connect them to resources to support what is deemed by the council to be important and meaningful to advance towards the ideal patient experience. This could look like doing collaborative outreach projects that are initiated

by patient-family advisors, research that is driven by the council, or family advisors serving on selected organizational committees for chosen quality projects.

This effort, while requiring a great deal of commitment and energy also created energy. It was a glorious opportunity for personal and professional growth. We tapped into a reservoir of staff interest and passion for diversity at the organization.

Simultaneously, this project responded to the community hunger for dialogue with the organization. I returned home from meetings feeling energized that the endeavor was meaningful and worthwhile. This quote by anthropologist, Margaret Mead, speaks to the meaning and purpose of this project well: “Never underestimate the impact of a small group of like-minded individuals in changing the world” (Applewhite, Evans & Frothingham, 2003). I believe that “like-minded individuals” translates to people who are committed to a mutually shared interest like advancing the ideal patient experience in healthcare for all to benefit.

## **Summary**

There are several compelling reasons to develop care models which provide family- centered, culturally congruent care. As discussed in chapter one, these reasons include the nation’s growing cultural diversity, the persistence of healthcare inequities that continue to disproportionately affect ethnic minorities, and multiple legislative, regulatory and accreditation mandates.

Bridge to One World honors the wealth of knowledge that family advisors bring to the group. Particularly, the model incorporates their knowledge of their community’s values, strengths, concerns and barriers to health. Bridge to One World offers a way to translate and connect the voices for better understanding to drive positive change. As

the Bridge to One World model is shaped by wisdom and compassion, the council is designed to carry a strong sense of purpose and meaning to nourish the group forward.

In the critical moments and challenges of life, we need an expanded conceptualization of “vital signs” for patients and families. Adoption of an Indigenous wisdom-practice model to create a compassionate, healing environment will improve the healing experience for diverse populations and all who seek care at the organization. Transcultural nursing expertise is a voice for human dignity and compassionate care in a challenging health system. The transcultural nurse leader can be the health interpreter and weaver of support networks to walk alongside families in their journey through the complex health organization.

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